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DOI:

[10.1093/intqhc/mzy024](https://doi.org/10.1093/intqhc/mzy024)

Document Version

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Citation for published version (APA):

Harrison, R., Walton, M., Kelly, P., Manias, E., Jorm, C., Smith-Merry, J., Iedema, R., Luxford, K., & Dyda, A. (2018). Hospitalization from the patient perspective: A data linkage study of adults in Australia. *International Journal for Quality in Health Care*, 30(5), 358-365. <https://doi.org/10.1093/intqhc/mzy024>

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HOSPITALISATION FROM THE PATIENT PERSPECTIVE: A DATA LINKAGE STUDY OF ADULTS IN AUSTRALIA

ABSTRACT

Objective: Evidence of the patient experience of hospitalisation is an essential component of health policy and service improvement but studies often lack a representative population sample or do not examine the influence of patient and hospital characteristics on experiences. We address these gaps by investigating the experiences of a large cohort of recently hospitalised patients aged 45 years and over in New South Wales (NSW), Australia who were identified using data linkage.

Design: Cross-sectional survey.

Setting: Hospitals in New South Wales, Australia.

Participants: The Picker Patient Experience Survey (PPE-15) was administered to a random sample of 20,000 patients hospitalised between January and June 2014.

Main outcome measure: Multivariable negative binomial regression was used to investigate factors associated with a higher PPE-15 score.

Results: There was a 40% response rate (7,661 completed surveys received). Respondents often reported a positive experience of being treated with dignity and respect, yet almost 40% wanted to be more involved in decisions about their care. Some respondents identified other problematic aspects of care such as receiving conflicting information from different care providers (18%) and feeling that doctors spoke in front of them as if they were not there (14%). Having an unplanned admission or having an adverse event were both very strongly associated with a poorer patient experience ($P<0.001$). No other factors were found to be associated.

Conclusions: Patient involvement in decision-making about care was highlighted as an important area for improvement. Further work is needed to address the challenges experienced by patients, carers and health professionals in achieving a genuine partnership model.

Keywords: patient experience; patient-centred care; patient surveys; hospital patients; Picker Patient Experience Survey

BACKGROUND

Patient experiences are an integral source of knowledge and can contribute towards policy development and service planning. Information from patient experience data contributes to understanding issues concerning care quality, including coordination of care, the care environment and provision of treatment.¹⁻³ A recent systematic review has shown that patients' *'direct experience of [the] care process through clinical encounters or as an observer'* (pg. 2) is associated with improved clinical effectiveness and patient safety.¹ Good patient experience has also been positively associated with medication adherence, appropriate use of screening services and reduced use of healthcare resources.¹

International patient experience surveys have identified some consistent aspects of care that patients and families find problematic, including the provision of emotional support, respect for patient preferences and involvement in decision-making.^{4,5} Such findings reflect clinicians' failure in responding empathetically to the emotional distress of patients.^{6,7} These findings also align with policy documents from the UK, USA and Australia, which highlight the need to better identify and respond to patient preferences and involve them in decision-making.⁸⁻¹¹

Establishing the exact nature of patient experiences is challenging.^{8,9,12-14} Patient experience surveys are used across Australia, but the content and method of administration varies.^{15,16-18} A recent review of the surveys conducted within Australian hospitals highlighted the diverse questions included a combination of experience and satisfaction items.¹⁶ Exploration regarding the patient and admission characteristics that impact on patients' experiences is limited. Whilst the experience of an adverse safety event may cause distress, the influence of such events on patient experience has not been investigated.^{19,20}

The present study uses linked data to identify recently hospitalised patients in NSW and captures their experiences using the Picker Patient Experience Survey (PPE-15) to enable international comparisons.²¹ The study explores the influences of patient age, gender, language, level of education, admission status and the impact of adverse events on experience and compares patients' experiences in hospitals in Australia to those captured using the PPE-15 internationally. It has the following objectives:

1. To determine positive and negative patient experiences in hospitals located in the state of NSW, Australia.
2. To describe the patient, professional and hospital characteristics associated with positive and negative patient experiences.

Methods

Ethics approval

The 45 and Up Study received ethics approval from the UNSW Human Research Ethics Committee. This sub-study received ethics approval from the NSW Population and Health Services Research Ethics Committee.

Design

Cross-sectional survey. The protocol has been published.²²

Setting and participants

The study utilised the Sax Institute's 45 and Up Study cohort of older adults in Australia, which includes a database of 267,153 citizens aged 45 and over. Prospective 45 and Up participants were randomly sampled from the Department of Human Services enrolment database, which provides near complete coverage of the population. People aged 80 and over and residents of rural and remote areas, were oversampled. Those who agreed to participate completed a baseline questionnaire (between Jan 2006 and December 2009) and gave signed consent for follow-up and linkage of their information to routine health databases.²³

Participants for the study described in this paper were a randomly selected sample of 20,000 individuals within the 45 and Up cohort who were hospitalised in NSW between January and June 2014. They were identified using data linkage via the Centre for Health Record Linkage (CHeReL) with the Admitted Patient Data Collection (APDC), which is administered by NSW Health and captures patients in public district and tertiary hospitals, and private hospitals. They provided additional consent.

Sample size

The sample size calculation was based on six month NSW hospital data from July-December in 2007 which recorded that 18,460 public hospitalisations had occurred in 45 and Up Study cohort. Given that hospitalisation rates were expected to rise every year as the cohort ages; we estimated there would be at least 20,000 hospitalisations in 45 and Up Study cohort for the six-month period from January 2014 to June 2014. We anticipated a 60% response rate, based on response rates to previous 45 and Up conducted questionnaires, yielding an estimated 14,000 respondents. A sample size of 14,000 would give very narrow 95% CIs for percentages: a maximum CI total width of 1.7%

Procedure

The Centre for Health Record Linkage (CHeReL) is a NSW Ministry of Health agency. CHeReL linked data from the Admitted Patient Data Collection with the 45 and Up Study Database to identify participants who were hospitalised in the study period using hospital admission data. CHeReL perform data linkage for research teams to then utilise to undertake data analysis. After the initial linkage, the 45 and Up Study team randomly selected 20,000 participants from their cohort who had a hospital admission in the six-month period from 1 January to 30 June 2017, and who were known to be alive in August 2017.

This sample was sent a survey pack including an invitation letter, a participant information leaflet and the survey with a perforated consent form. People from CALD backgrounds or others who might have difficulty reading in English were advised to seek help from a friend or relative. Those who wished to participate completed the consent form and returned their completed

survey to the 45 and Up Study using the reply-paid envelope. Surveys without a signed consent form were not forwarded to the research team.

Survey tool

The PPE-15 is a 15-item, internationally validated survey tool for capturing patients' experiences in hospital.^{21,23} The PPE-15 calculates experiences based on the number of 'problems' experienced in care. Each item is coded as to whether it identifies the presence or absence of a problem in care, with a problem being '*an aspect of health care that could, in the eyes of the patient, be improved upon*' (pg. 354).²¹ Administration of the PPE-15 was included as part of a larger survey that explored patients' experiences of adverse events in hospitals that has been reported elsewhere.²⁴ The survey therefore also captured self-reported data about any incident that the patient believed to be an adverse event. The definition used was 'an event or circumstance during health care caused by the hospital which could have or did result in unintended or unnecessary harm to you.' This definition was based on commonly-cited definitions of adverse event, but modified to be appropriate to a lay audience with the key aspects retained of: 1) unintended or unnecessary, 2) harm resulting and 3) caused by the healthcare provider (in this case, the hospital).²⁵⁻²⁷

Analytic strategy

The frequency and percentage was summarised for each PPE 15 item. A score was also created for each PPE-15 item by coding the item response '2' if a problem was indicated, '1' if a problem was partially indicated or '0' if no problem was indicated. For example, on the item 'When you had important questions to ask a doctor, did you get answers you could understand?'

a response of ‘yes, always’ was awarded 0, ‘yes, at times’ was awarded 1 and ‘no’ was awarded 2. Overall scores were calculated for each patient by summing scores from each item, with a maximum possible score of 30. Based on the approach by Jenkinson et al (2002), items which were not applicable or had a missing value, were assumed to be no problem and given a score of 0. An overall score close to 0 indicated a better experience with fewer problems in care, while higher scores indicated a poorer experience with more problems in care.

Stata-MP (Stata Statistical Software: Release 12 College Station, TX: StataCorp LP) was used for all analyses. Patient characteristics and individual PPE-15 items were summarised as frequencies and percentages. Multivariable negative binomial regression was used to determine whether patient age, gender, cultural and linguistic diversity, level of education, or admission status (emergency or planned) were associated with the overall PPE-15 score. The regression items were included based on our systematic review of patient experience of adverse events and key papers that identify patient age, gender, cultural and linguistic diversity, level of education, or admission status (emergency or planned) as factors affecting adverse events.¹⁹ All variables were included in the model. Interactions were tested between those who reported an adverse event (AE) and the other variables in the model. Due to the large sample size, a significance level of 0.01 was used to claim association. Only complete cases were included in the model; data were not imputed. A sensitivity analysis was conducted by comparing the model with and without local health district area (LHD).

Results

Preliminary analysis

We have reported previously the cohort selection and its characteristics.²⁴ In brief, of the 20,000 identified participants from the 45 and Up Study, 18,993 were eligible to participate. Ineligible individuals included those who had since deceased (189), those whose postal survey was returned to sender (640), and those who responded indicating that the data linkage was incorrect, as they had not been admitted to hospital on the specified date (178). Completed surveys were received from 7,661 of the 18,993 (40% response rate).

No differences existed between responders and non-responders in regards to age, gender, English not as their only language, local government area or level of education, as reported in our earlier paper.²⁴ Table 1 re-presents a summary of the overall cohort characteristics from the earlier paper.

Positive and negative patient experiences in hospitals located in the state of NSW, Australia

Table 2 presents the frequency and percentage of responses to each PPE-15 item. The frequencies are reported based on all those who responded to each item and for whom the item was applicable, therefore the number of responses for each item varies. Patients mostly described a positive care experience, reporting they received clear answers to questions from doctors (6,034; 85.6%) or nurses (5648; 81.8%) all of the time, and 6,879 respondents (90.8%) reporting feeling treated with respect and dignity all of the time they were in hospital. Most respondents (2,465; 80.9%) reported that the hospital staff did everything they could to help control their pain and 74.0% (3,607) reported that doctors or nurses gave their support person all the information they needed in order for the respondent to recover.

In all, 1321 respondents (17.5%) reported receiving conflicting information from different care providers at least some of the time. Furthermore, 1,088 (14.4%) respondents felt that doctors spoke in front of them as if they were not there (at times or always). In addition, 2,972 respondents (39.3%) indicated a desire to be more involved in decisions about their care. The purpose of medications being taken home was always explained to 4,040 respondents (82.1%), but medication side effects were discussed fully with only 2,230 respondents (57.6%).

A total of 1,899 (24.8%) of participants reported an overall PPE-15 score of zero, indicating no problems experienced in care, with 2,146 (28.0%) reporting a PPE-score of one or two. Thus 52.8% (4,045) of patients recorded a score of two or less. A total of 10.2% (783) participants reported a PPE-score of 10 or more, and 3% (230) recorded a score of 15 or more (Figure 1).

Patient, professional and hospital characteristics associated with positive and negative patient experiences.

Having an unplanned admission or having an AE were both associated with a higher overall PPE-15 score ($p < 0.001$). There was no association between overall score and any other variables in the model (Table 3). However, there was a significant interaction between self-reported AE and type of admission (interaction $p = 0.004$), type of admission was an effect modifier for the effect of AEs on overall PPE-15 score (Table 3). Those who had a planned admission and had an adverse event had scores 2.75 times higher compared to those who had a planned admission without an adverse event (95%CI 2.41-3.11). Scores were also 1.84 times higher if the admission was unplanned compared to a planned admission (95%CI 1.73-1.95). However, scores

were highest, 3.75 times higher, if the admission was both unplanned and the patient experienced an adverse event (95% 3.21-4.38). The results did not qualitatively change with inclusion or exclusion of LHD in the model (statistical significance did not alter and <10% change in estimated relative risks).

Discussion

Our data present a positive view of adults' experiences in NSW hospitals in terms of communications with health professionals, pain management and being treated with dignity and respect; indicating some success in efforts to promote positive patient experiences in NSW hospitals.²⁸ Yet substantial numbers identified problematic aspects of care, with around 40% indicating a desire to be more involved in decisions about their care despite substantial recent policy development nationally and internationally around patient-centred care and shared decision-making.²⁹

Our findings reflect those of the NSW Bureau of Health Information, who identified that 40% of patients were not as involved as they wanted to be in their care.³⁰ Promoting patient involvement has been the focus of a number of initiatives in Australia. The 'Partnering with Patients' program devised by the NSW Clinical Excellence Commission aims to 'support local health districts (LHDs) across NSW to transform services, by including patients, family and carers as health team members and to champion consumer engagement with the aim of improving safety and quality in health care.'³¹ Yet barriers clearly remain.³² Challenges include engaging with patients

for whom English is not their first language, who are experiencing severe health problems or who have cognitive impairment.³³ Lack of clarity regarding the extent to which family members' wishes are to be met and around decision-making when patients, carers and healthcare providers hold contrasting views, also inhibits engagement.³⁴

This study provides the first large-scale evidence linking unplanned admissions and the experience of an adverse event (regardless of event severity) with a poorer patient experience. Our data reflect existing evidence that patients who have an unplanned admission have higher adverse event and error likelihood.³⁵ The finding may be explained in part because those with unplanned admissions are often in poorer health, experience an acute health issue and enter the hospital via the emergency department. Time and resource pressures, the complexity of patients' health problems, the need for urgent diagnosis and action, and the frequency of invasive interventions are all greater in emergency settings.³⁷⁻³⁹ These factors, along with the lack of continuity in care in emergency settings, are all likely to impact on the patient experience.^{40,41}

The use of the Picker Patient Experience enables our findings to contribute to international comparisons. A review of patient surveys in OECD and non-OECD European Union member countries identified 55 national or cross-national surveys of patients experiences and highlighted the value of utilising consistent survey methodology across locations to identify opportunities to learn from national and international efforts to enhance care quality.⁴² **In addition,** data from the Picker items used in the NHS 2014 survey of 59,000 inpatients reported 81% of UK patients as being treated with dignity and respect (compared to our 91%), with 35% not being advised of specific problems related to their condition to look out for when they went home (compared to

only 13% in our sample).⁴³ Over 40% of UK patients also reported that the purpose of their medications was not explained clearly to them on leaving hospital, in comparison to 20% of the NSW sample.⁴³ The greatest disparity between our findings and results from the UK related to patient involvement. Almost half of Australian respondents wanted to be more involved in decisions about their care, compared to only 10% of UK respondents.⁴³ This may be due to the fact that UK patients are either more involved in their care, or that they are more satisfied with the level of involvement they have. Potential for differences in data quality, reliability and validity between locations is also acknowledged as a possible factor in these disparate findings.⁴²

Our findings indicate that patients in NSW were somewhat more satisfied with their experiences of information provision around medications than older adults in other locations. In a study of patients aged ≥ 60 with chronic disease conditions (or their caregivers) in Hong Kong, around half of patients (53%) felt that healthcare staff or clinic pharmacists had clearly explained administration instructions of prescribed medications and the medication's purpose (48%). Yet, only 11.4% felt they had very clear explanations of side-effects, which was much lower than in our study.⁴⁴ In the UK, interviews following hospital discharge with people aged over 75 who were taking four or more medicines (and their carers) revealed participants were dissatisfied with inadequate explanations about medicines at discharge.⁴⁵ There were also important omissions of medicines, incorrect dosages, and the creation of a state of anxiety and confusion.⁴⁵

Implications

These findings reveal a disconnect between Australian patients' expectations of involvement and their experiences. Current measures to promote patient involvement in Australian hospitals may

be insufficient. Patient involvement in the development and delivery of healthcare services is central to healthcare policy in many countries.^{9,11,43} For example, the UK Health and Social Care Act 2012 highlights the responsibility of the NHS Commissioning Board and clinical commissioning groups to promote patients involvement in decisions, and to facilitate patient choice.⁴⁷ Patient involvement can contribute to changes in provision of services across a range of health and social care settings.^{47,48} Involving patients in decision-making is one critical aspect of patient involvement. Healthcare professionals often subscribe to the notion of shared decision making, but fall short in its practice due to misconceptions about what it entails.^{49,50}

Support is required for patients and health care providers to make shared decision-making a reality. Literature with associated tools has emerged that aims to enhance and support shared decision-making between patients and practitioners, but barriers to this process remain.⁴⁹⁻⁵¹ Australian health professionals may benefit from more focused education and training in how to involve patients in their care and how to support patients to engage with health services. Specific steps might include addressing barriers faced by culturally and linguistically diverse patients through provision of appropriate translation services and by providing clear and consistent guidance for clinicians in managing differences of opinion to facilitate shared decision-making. Real-time feedback devices are being trialed, allowing patients and family members to report issues as they go through care, enhancing their involvement. Consumers have also been employed at quasi-management levels to help orient organisations at a systemic level towards patient involvement.⁵²

Our approach also provides an opportunity to further develop methods used to report patients experiences. The 2008 OECD review highlighted the need to capture and distinguish experiences of particular patient groups.⁴² Data linkage with admitted patient data provides one strategy for doing this that does not rely on patients self-identifying, particularly for this with co-morbidities or chronic conditions that are well-documented in such data.

Limitations

Using the 45 and Up sample greatly improved our ability to access a guaranteed sample population and was suitable given that the majority of patients hospitalised in Australia are over 45.⁵³ The 45 and Up Study is potentially not representative of individuals from culturally and linguistically diverse (CALD) backgrounds. For example, while 25% of the 45 and Up Study were born outside of Australia, 2006 census data puts this figure at 39% for those aged 45 and over in NSW.⁵³ However, analysis of the subset of surveys we receive from CALD participants revealed no significant differences between the experiences of CALD and non-CALD participants. The survey did not capture the experiences of some important groups including patients who died, patients who did not have the capacity to consent and the family or carers of hospitalised patients. Whilst the 40% response rate achieved is a possible limitation, no demographic differences were detected between responders and non-responders.

Conclusion

Patients in NSW hospitals report positive experiences of many aspects of their care, which compare favourably with those in other countries. Patient involvement in decision-making about care was highlighted as an important area for improvement; a substantial proportion of patients

wanted to be more involved. Work is needed to address challenges experienced by patients, carers and health professionals in working towards a genuine partnership model.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All of the listed authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; drafting the article or revising it critically for important intellectual content; and to the final approval of the version to be published as set out in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals.

Funding statement

This project was funded by a National Health and Medical Research Council (NHMRC) Project Grant No. 1049703.

Acknowledgments

This research was completed using data collected through the 45 and Up Study (www.saxinstitute.org.au). The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW; and partners: the National Heart Foundation of Australia (NSW Division); NSW Ministry of Health; NSW Government Family & Community Services – Ageing, Carers and the Disability Council NSW; and the Australian Red Cross Blood Service. We thank the many thousands of people participating in the 45 and Up Study.

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